# GUIDING QUESTIONS FOR THE NORMATIVE FRAMEWORK OF THE ISSUES EXAMINED AT THE IX SESSION OF THE OPEN-ENDED WORKING GROUP ON AGEING:

**Long-term and Palliative Care**

**Portugal**

**National legal framework**

1. **What are the legal provisions in your country that recognizes the right to long-term and palliative care? Do they have a constitutional, legislative or executive foundation?**

Law 52/2012, of 5 September – Basic Law on Palliative Care, enshrines the right to palliative care and regulates citizen’s access, defines the State responsibility and creates the National Network.

<https://data.dre.pt/eli/lei/52/2012/09/05/p/dre/pt/html>

# Normative elements

1. **What are the key normative elements of the rights to long-term and palliative care? Please provide references to existing laws and standards where applicable.**

The Decree-Law 101/2006, of 6 June establishes the **National Network for Continued Integrated Care** under the joint responsibility of the Ministry of Health and the Ministry of Labour, Solidarity and Social Security, with a focus on the coordination and organisation of “long-term care”. It defines an integrated and/or articulated model of health and social security of a preventive, recuperative and palliative nature, involving the participation and collaboration of several social partners, civil society and the State. This model stands as a new intermediate level of health care and social support, between community-based and inpatient care. It advocates the implementation of care units and teams to support people in dependency situations. The model is also based on a typology of appropriate responses by social, public and private partnerships. The National Network for Continued Integrated Care is organized in two territorial levels of operationalization, regional and local.

The provision of **continuous long-term mental health care** is cared for in Decree-Law 8/2010, of 28 January, and Decree-Law 22/2011, of 10 February.

1. **How should *long-term care* and *palliative care* be legally defined?**

In the Portuguese legislation these concepts are defined in the Chapter I of the Law 52/2012, of 5 September – Basic Law on Palliative Care.

(see: <https://data.dre.pt/eli/lei/52/2012/09/05/p/dre/pt/html>)

# Implementation

1. **What are the policies and programmes adopted by your country to guarantee older person’s enjoyment of their right to long-term and palliative care?**

The National Network for Continued Integrated Care 2016-2019 Development Plan, foresees:

* Improving the living conditions and well-being of dependent persons through the provision of continued health care and/or social support;
* Keeping people with loss of functionality or at risk of losing functionality at home, provided that through home support they can be guaranteed the therapeutic care and social support necessary for provide and maintain comfort and quality of life;
* Support, monitoring and hospital care technically appropriate to each situation;
* Continuous improvement in the quality of the long-term health care and social support;
* Support for family members or informal caregiver in their qualification and care provision;
* The networking and coordination of care in different services, sectors and levels of differentiation;
* The prevention of gaps in services and equipment, through progressive coverage at a national level of the needs of dependent persons in terms of integrated long-term care and palliative care.

The National Mental Health Programme, includes several actions/projects:

* Training for health professionals in the provision of care for people with Alzheimer’s disease and other dementias (Alzheimer Portugal Association);
* Project: Identification of problems and psychosocial needs of elderly people in Day Care Centres and Residential Homes;
* Project: Characterisation of functional and biological factors with an impact on cognitive decline in the Portuguese Population (Cell Biology Neuroscience Centre, University of Coimbra);
* Incidence study of cognitive deficit and dementia in a representative sample of the Portuguese population (Research Centre of the Cognitive and Behavioural Studies and Intervention Centre of the Faculty of Psychology and Educational Sciences, University of Coimbra);
* Training of formal carers of elderly people in nursing homes (Escola Superior Dr. Lopes Dias, Polytechnic Institute of Castelo Branco);
* CuiDem Project - Care for Dementia (Centro de Atendimento 50+);
* Survey on the care situation of older people in the field of psychiatry and mental health and opinion questionnaire on forms of dementia;
* MentHA - Mental Health Ageing (Centre for Research and Development at the Beira Association).

1. **What are the best practices and main challenges in adopting and implementing a normative framework to implement these rights?**

The Portuguese National Network for Continued Integrated Care (RNCCI), was set up in 2006, under the joint responsibility of the Ministry of Health and the Ministry of Labour, Solidarity and Social Security. It focus on the coordination and organization of “long-term care” providing structured responses to people in a state of dependency, at different levels of functionality in all life stages.

In 2016, the Government established as one of its priorities the expansion and improved integration of this Network. The National Coordination Commission of the RNCCI was created for this purpose and the RNCCI 2016-2019 Development Plan was presented. Ten years after, it is evident that most of its users are elderly (about 85%). It is therefore important to pay special attention to understanding the ageing process with all its determining factors and also to structure and extend the response to other age groups and other conditions, such as severe mental illness and dementia, situations with a very broad clinical spectrum and the need of very specific responses. There are plans to improve and increase capacity and type of responses along with a better understanding of the phenomena of ageing and dependency and its associated needs. Areas identified are strengthening the outpatient component of the RNCCI, through the implementation of Day Care Units in the field and the Promotion of Autonomy. It is an outreach response and its implementation must be based on knowledge of the territory, transport links, social economic characterization and preferences of patients and their families.

# Equality and non-discrimination

1. **Which are the measures adopted to ensure equitable access by older persons to the enjoyment of the right to long-term and palliative care, paying special attention to those who are vulnerable or in vulnerable situation?**

National regulation of the procedures guaranteeing equitable access to the right to long-term care:

* + Model that defines the criteria for assessing access to RNCCI
  + Centralized Model of Job Placement and Management
  + Direct Family Financing Model

<http://www.seg-social.pt/documents/10152/27195/N37_rede_nacional_cuidados_continuados_integrados_rncci/f2a042b4-d64f-44e8-8b68-b691c7b5010a>

# Participation

1. **Does the design and implementation of normative and political framework related to long-term and palliative care include an effective and meaningful participation of older persons?**

Regulation of the following procedures that guarantee the effective participation of long-term care:

* + Signing of the Acceptance Agreement
  + Signature of Informed Consent
  + Preferential Choice option of the Long-Term Care Unit
  + Participation in the Individual Care Plan

# Accountability

1. **What judicial and non-judicial mechanisms are in place for older persons to complain and seek redress for denial of their right to long-term and palliative care?**

Mechanisms include administrative procedures of appeal (it is always possible to appeal against decisions of the public administration, including those taken by Social Security institutions, the Health Regulatory Body, the RNCCI Coordination Teams, the National Coordination Commission of the RNCCI), along with the right to use judicial procedures and/or to complain to the ombudsman (*Provedor de Justiça*). Letters to ministers and to the Presidency of the Republic are also always taken into account.